Validity, reliability and responsiveness of the Thai Palliative Care Outcome Scale staff and patient versions among cancer patients

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Abstract

Background: Palliative care is now part of Universal Health Coverage goals. Measurement of person-centred outcomes is central to determining quality and effectiveness. Guidance in psychometrics requires tools applied in new settings to have their properties tested.

Aims: To translate staff and patient versions of the Palliative care Outcome Scale (POS version 2) into Thai, and to determine its psychometric properties among cancer patients in a Thai public hospital.

Design: The Thai POS was subjected to cross-cultural translation: forward translation, backward translation, review by experts, and content validity index measurement. The patient-rated version was completed by N=379, and staff-rated version by N=379 nurses. We tested internal consistency, known-group comparison, responsiveness, and agreement.

Setting/participants: n=379 Thai cancer patients admitted to Maharaj Nakorn Chiang Mai Hospital.

Results: We found good internal consistency (Cronbach's alpha=0.9), good discrimination between known groups (significant difference in scores between high and low performance status groups, Z ranged from -9.95 to -7.80, $p<0.001$), good responsiveness (improvements in at time 2, Z ranged from -14.01 to -6.31, $p<0.001$)**,** and acceptable to good patient-staff agreement on ratings (weighted kappa range 0.31 to 0.73).

Conclusion: The Thai POS is valid and reliable. These findings enable researchers and clinicians to apply the POS in primary research and routine clinical practice, to both determine the effectiveness of interventions and improve care. This is the first validation in the region of a multidimensional person-centred outcome measure designed specifically for patients and families with advanced disease.

Introduction

Despite an estimated 93.7 cancer-related deaths per 100,000 population in Thailand (1), provision of palliative care is not yet fully integrated into the health system (2). The quality of death in Thailand is ranked 44th among 80 countries (3). While much has been achieved, palliative care provision in Thailand must be improved to meet the WHO's Universal Health Coverage goals (4).

Patient-centred outcome measures (PCOMs) are an important mechanism to achieve quality and equity in health care (5), and are a route to reducing global inequalities in palliative care (6, 7) by enabling patients to raise concerns with health professionals and focusing on outcomes (8). Use of PCOM results in palliative care can increase referrals, improve symptom recognition, increase discussions on quality of life, and improve emotional and psychological patient outcomes (9).

Outcome measures in palliative care must be specific to the symptoms and concerns related to incurable illness, and be adequately brief for completion (10). To ensure use of outcome measures in the field of palliative care that are consistent, and that reflect the concerns of our patient and family population, we should use existing tools that have sound properties rather than developing new ones (11). The palliative care measures revalidated in Thailand to date (Edmonton Symptom Assessment Schedule (12) and the Palliative Performance Scale (13)) do not cover all important domains in palliative care (14). The Palliative Outcome Scale (POS) is one of the most commonly used tools in research and clinical practice (15). This instrument is a core outcome measure assessing physical, psychological, social, and spiritual domains of palliative care patients. Additionally, the POS consists of patient-rated and staff-rated questionnaires which can obtain information directly from patients or alternative information from staff when patients are too ill to complete a questionnaire by themselves. This strength is not found on other palliative care measures in Thailand. A review of the

theoretical dimensions concluded that the POS is one of the most valid, reliable and comprehensive tools in palliative care (16). It has a stable factor structure (17) and good sensitivity and specificity when screening for depression (18). POS is used to assess interventions, prevalence of symptoms, and palliative care needs among patients with cancer and non-malignant diseases in high, middle and low income countries (19, 20) and has good validity and reliability (21).

When health measurement scales are used in populations outside their original validation, the psychometric properties may not remain constant (22). This study aimed to translate the POSv2 patient and staff versions into Thai, and to evaluate its psychometric properties: construct validity (known-group comparison), internal consistency, responsiveness, and patient-staff agreement on ratings.

Methods

We conducted this validation study in line with the COSMIN guidance (23), and the COSMIN quality checklist (24). COSMIN provides international consensus on taxonomy, terminology and definitions of health outcome measure properties to evaluate outcome measures in health care..

Setting/participants

We recruited cancer patients admitted to Maharaj Nakorn Chiang Mai hospital referred to the Chiang Mai University hospital-based palliative care service. This service is delivered by a multidisciplinary health care team in order to manage physical, psychological, social and spiritual problems, in collaboration with local health service centres for continuity of care. Inclusion criteria were: patients diagnosed with cancer, receiving palliative care, able to

respond to questions in Thai, with sufficient cognitive and physical capacity to participate, and to provide written informed consent.

Instrument

The original POS V2 is an 11-item rating scale consisting of the staff and patient versions. 10 items are used to assess physical symptoms, psychological symptoms, social problems and spirituality. The 11th item is an open-ended question asking about other problems.

Cross-cultural translation

POS V2 was selected by the clinical team as the preferred outcome measure due to its brevity and use of an open question. Cross-cultural translation consisted of forward translation, backward translation, review by experts, and pre-test, following best practice guidance (25). In this validation study we also asked the nurse to complete the Palliative Performance Scale (PPS) at Time 1 and 2 (26), as this is specific to palliative care and has been validated in Thaland (13), enabling us to conduct known-group comparison. .POS V2 was translated into Thai by the first bilingual translator (a palliative care nurse). This was edited by the second bilingual translator (a linguist). This was back translated into English by the third bilingual translator (a linguist) who had not seen the original version.

Comparison between the back-translated version and the original English version was conducted by the first two translators to examine the semantic, content and conceptual equivalence between these two versions (27). When any discrepancy between these two versions was identified, the back-translated version, and also the Thai version, were then modified by consensus from these two translators. The modified back-translated version was sent to POS research team (King's College London) for external review, with no further suggested edits.

A pre-test was conducted to examine content validity and internal consistency. Five palliative care professionals reviewed both patient-rated and staff-rated questionnaires, and the content validity index (CVI) was calculated. 15 patients and nurses were asked to complete a patient-rated and staff-rated questionnaire respectively, then internal consistency was calculated.

Data collection

Patients were recruited within three days of admission. Demographic data were collected through self-report and chart review. At T1 the patient asked to self-complete the patient version (with assistance as required), and the staff version was completed by their allocated nurse. At seven days, the same staff and patients completed a second POS (T2), and at a further seven days a third POS was completed (T3). Therefore the same nurse reported data on the patient at each timepoint. Data were entered into SPSS v22 for analysis.

Analysis

The exploration of validity and reliability followed best practice guidance for health measurement validation (23, 28). Before testing the psychometric properties, POS scores in this study were reversed for comparison with PPS scores (therefore higher POS scores reflected better outcomes and lower scores reflected worse outcomes). For construct validity, known-group comparison was tested. Known-group comparison sought to determine whether patients with low performance status (PPS scores below median) had total POS scores statistically significantly lower than patients with high performance status (PPS scores ≥ median). Because POS scores were non-normally distributed, Mann-Whitney U-test was used to evaluate whether total POS scores of were significantly different. A statistically significant level of $p \leq 0.05$) would indicate adequate discrimination between known groups.

Internal consistency was evaluated by using Cronbach's alpha, with a result ≥ 0.7 adequate to indicate adequate internal consistency (30). Responsiveness was assessed by observing

changes in POS scores over time. Changes in POS scores were examined (total score and for each item) between the first and the second assessment, and between second and the third assessment. Because scores were non-normally distributed data, Wilcoxon signed rank test was used to test the hypothesis that a statistically significant change would be observed between timepoints.

The agreement on ratings was determined for staff and patient-report at each timepoint. . The level of agreement for each item was assessed by calculating the percentage of agreement and Cohen's linear quadratic weighted kappa, hypothesized to be ≥ 0.61 for at least substantial agreement (31).

This research was approved by the Research Ethics Committee, Faculty of Medicine, Chiang Mai University (Research lD:945 / Study code No. NllR 12 945 EX).

Results

Sample characteristics

We recruited N=379 patients with an average age of 53.9-years (see Table 1). Most patients had low education, low income, and received their clinical care through Government public welfare. The most common malignancies were bronchus and lung, liver and colon. The median PPS score of this sample was 80.

INSERT TABLE 1 HERE

Completeness of data

POS data had very high levels of completion at the item level (see Tables 2 and 3) at Time 1 and Time 2 (98.4-100% of items complete). However, only 45% of data could be collected at T3 because patients had been discharged.

Content validity

The averaged CVI was reported as 0.96 for patient version and 0.95 for staff version, demonstrating good validity (32).

Construct validity: known-group comparison

At T1 and T2, total POS scores for the high-performance status group were significantly higher than those in the low-performance status group for both patient and staff versions (Z ranged from -9.95 to -7.80, $p<0.001$).

Internal consistency

Cronbach's alpha at pre-test was 0.87 (n=15) for staff version and 0.89 (n=15) for patient version, and at T1 was 0.91 (n= 378) for staff version and 0.90 (n=379) for patient version, indicating good internal consistency (0.7-0.9=good internal consistency) (30).

Responsiveness

For responsiveness T1-T2, statistically significant changes were demonstrated for total score and all POS items (see Table 2 for staff version and Table 3 for patient version). For responsiveness T2-T3, there were statistically significant changes of total scores and all POS items scores except for the item “wasted time” in the staff version.

INSERT TABLE 2 HERE

INSERT TABLE 3 HERE

Agreement on ratings

At T1 and T2, the percentage of total agreement for all items ranged from 50.4% to 81.2%. Cohen’s weighted kappa of most items ranged from 0.46 to 0.73, indicating moderate to substantial agreement. The weighted kappa for items “family anxiety” and “wasted time” at T2 ranged from 0.31 to 0.35 which indicates fair agreement (31) (see Table 4).

INSERT TABLE 4 HERE

Discussion

This is the first validation of the POS in Southeast Asia (19, 20) and reports a large sample size.

High CVI demonstrated in the pre-test confirmed that the Thai POS comprehensively represented palliative care outcomes in Thai culture, and was accepted by experts (33, 34). Additionally, the known-group comparison showed that the Thai POS can discriminate between patients with different clinical status (36).

High internal consistency confirmed that items in the Thai translation of POS measure a similar concept (37). When compared to the original version, the internal consistency of the Thai POS is higher (Cronbach’s alphas of the original version = 0.65 and 0.7 for patient-rated and staff-rated questionnaire, respectively) (21). The explanation for this finding may be that

Thai patients may be more likely to have the mind-body linkage, compared to Western patients (where the original POS was developed). This explanation is supported by a study of symptom clusters in Thai cancer patients which found that pain, other physical symptoms, anxiety and depression were in the same symptom cluster (38), contrary to a study of UK cancer patients which found that pain and most of the physical symptoms were not in the same cluster as anxiety and depression (39). A symptom cluster is defined as symptoms which occur together and possibly share the same aetiology or mechanism (40).

In terms of evaluating care, Thai POS is able to detect changes in outcomes (34) for all items. The assessment of patient-staff agreement on ratings demonstrated acceptable agreement for all items at T1 and for most items at T2, suggesting Thai POS is appropriate for use as a staff proxy for patients unable to self-report. Interestingly, substantial agreement was shown for the item “pain” at T1 and T2. This could be because pain is the hallmark of palliative care, distinguishing it from supportive care (41), it is most likely to have received careful monitoring and therefore awareness among staff. Although the item “family anxiety” and “wasted time” at T2 showed fair agreement (weighted kappa = 0.31 and 0.35 respectively), these kappas are within the range of weighted kappa for the original POS (0.22 to 0.58 at T1 and T2) (21). Additionally, kappas of these two items may be lower than actual values because the percentages of agreement of these two items were not particularly low (53.6 and 81.2). These paradoxical results may be caused by symmetrically unbalanced marginal totals for the contingency table of these two items (42).

When compared with the Thai ESAS, internal consistency of Thai POS is higher (Cronbach’s alpha of the Thai ESAS is 0.75) (12). Additionally, in the assessment of face validity of the Thai ESAS, patients reported that the range of the numerical scale (0 to 10) was too wide for measurement of emotion, and the meaning of each scale point should be explained (12). So, the ordinal scale in the Thai POS may be better because it contains fewer response levels and the meaning of each scale point is explained. Furthermore, Thai POS covers more

palliative care domains, including communication, psychosocial support, and spirituality, and can be rated by both patients and staff, although the Thai ESAS measures more physical symptoms. We note that the newest version of POS (the IPOS) has an expanded symptom list.

Some limitations of this study are that convergent validity, discriminant validity, test-retest reliability and appropriateness of Thai POS were not studied (although the very low amount of missing data during both patient self-complete and staff-complete suggests good appropriateness). For responsiveness, our analysis is based on an assumption of meaningful change within patients and we have no indicator of change other than the self-report POS data. Also, this study was conducted on only cancer patients admitted in a hospital, so the results may not be generalised to patients with chronic non-malignant diseases, and patients in other palliative care settings. Hence, future research should study these untested psychometric properties and should be conducted on a more heterogeneous population of adults with incurable progressive illness.

Conclusion

This study demonstrates that Thai POS is valid and reliable when used among Thai cancer patients. In the evaluation of psychometric properties, the results demonstrated that the Thai POS has good content validity, good discrimination between known groups, good internal consistency, good responsiveness, and acceptable patient-staff agreement on ratings. Furthermore, when selecting a tool to measure person-centred outcomes in palliative care in Thailand the Thai POS may be considered an appropriate choice as, compared to other measures, validated in Thailand it covers core domains of palliative care and has valid both patient and staff completion versions. We believe that the properties of the Thai POS will

enable clinicians to ensure that they direct and monitor care to reflects the priorities of patients and their families, support services to audit their provision of care, and at policy and Governmental level it can provide the evidence of effectiveness for models of care required by the World Health Assembly's resolution on palliative care (43). Local validation of outcome measurement in low and middle-income countries can also catalyse research activity and outputs (44, 45). The Thai POS should be widely used in clinical practice, audit and research to advance the field of palliative care.

Declaration of conflict of interest

The authors declare that there is no conflict of interest.

Table 1 Characteristics of patients

Number of patients	379	
Age Mean (SD) Min - Max	 53.9 (13.1) 15 - 89	
Gender Male Female	 199 (52.5%) 180 (47.5%)	
Marital status Married Single/Widow/Divorce/Separate	 253 (66.8%) 126 (33.2%)	
Education Primary or secondary school Bachelor or higher degree No education	 278 (73.4%) 84 (22.2%) 17 (4.5%)	
Income No income < 153 USD 153 – 307 USD > 307 USD	111 (29.3%) 118 (31.1%) 69 (18.2%) 81 (21.4%)	
Health coverage * Government public welfareWelfare for Government officer/Public enterprise officer Pay by personal money Others	 215 (56.7%) 118 (31.1%) 41 (10.8%) 4 (1.1%)	
Disease (Malignant neoplasm of) Bronchus and lung Liver Colon Hematopoietic tissue Head/Neck Bone and articular cartilage Lymphoid tissue Cervix uteri Breasts Others	 79 (20.8%) 63 (16.6%) 56 (14.8%) 33 (8.7%) 31 (8.2%) 30 (7.9%) 23 (6.1%) 22 (5.8%) 12 (3.2%) 30 (7.9%)	
PPS** score at Time 1 Median (interquartile) Min – Max	 80 (60 - 90) 30 – 100	

* Missing data for 1 case

268 ** PPS = Palliative Performance Scale

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270 **Table 2 Responsiveness to change of the POS; Staff version (tested by Wilcoxon signed rank test) N=379**

	Time 1			Time 2 (Responsiveness between time 2 and time 1)					Time 3 (Responsiveness between time 3 and time 2)				
	Mean (95% CI)	Median (Interquartile)	n	Mean (95% CI)	Median (Interquartile)	n	Z	p	Mean (95% CI)	Median (Interquartile)	n	Z	p
1. Pain	2.2 (2.07-2.34)	2 (1-3)	379	2.73 (2.65-2.81)	3 (2-3)	379	-8.33	<0.001	2.96 (2.89-3.03)	3 (3-3)	171	-6.57	<0.001
2. Other symptoms	2.28 (2.15-2.15)	2 (1-3)	379	2.78 (2.70-2.85)	3 (2-3)	379	-8.08	<0.001	3.32 (3.23-3.42)	3 (3-4)	171	-7.23	<0.001
3. Patient anxiety	2.34 (2.23-2.45)	2 (1-3)	379	2.86 (2.78-2.93)	3 (2-3)	379	-8.94	<0.001	3.06 (2.98-3.13)	3 (3-3)	171	-5.92	<0.001
4. Family anxiety	2.10 (1.98-2.22)	2 (1-3)	378	2.88 (2.81-2.96)	3 (3-3)	379	-10.36 [a]	<0.001 [a]	3.32 (3.21-3.43)	3 (3-4)	171	-7.09	<0.001
5. Information	2.59 (2.47-2.70)	2 (2-4)	379	3.21 (3.13-3.30)	3 (3-4)	379	-9.57	<0.001	3.55 (3.45-3.65)	4 (3-4)	171	-6.55	<0.001
6. Sharing feeling	2.29 (2.17-2.42)	2 (1-3)	379	2.88 (2.79-2.97)	3 (2-4)	379	-9.48	<0.001	3.19 (3.12-3.27)	3 (3-3)	171	-5.83	<0.001
7. Depression	2.56 (2.46-2.67)	2 (2-4)	379	2.91 (2.81-3.00)	3 (2-4)	379	-6.59	<0.001	3.11 (3.01-3.20)	3 (3-3)	171	-6.33	<0.001
8. Self-worth	2.49 (2.37-2.60)	2 (2-4)	379	2.98 (2.89-3.08)	3 (2-4)	378	-9.71	<0.001	3.30 (3.19-3.41)	3 (3-4)	171	-6.69 [c]	<0.001 [c]

9. Wasted time	1.61 (1.44-1.79)	2 (0-4)	379	3.67 (3.58-3.77)	4 (4-4)	378	-13.66 [a]	<0.001 [a]	3.80 (3.68-3.93)	4 (4-4)	171	-1.45 [c]	0.147 [c]
10. Personal affairs	2.49 (2.37-2.62)	2 (2-4)	379	2.91 (2.80-3.02)	2 (2-4)	379	-6.31	<0.001	3.25 (3.09-3.40)	4 (2-4)	170	-5.58	<0.001
Total	22.96 (22.01-23.91)	23 (13-32)	378	29.82 (29.27-30.37)	30 (26-34)	378	-14.01 [b]	<0.001 [b]	32.85 (32.27-33.44)	34 (32-34)	170	-9.68 [d]	<0.001 [d]

[a] 1 patient had missing data. [b] 2 patients had missing data. [c] 1 patient had missing data. [d] 2 patients had missing data.

274 **Table 3 Responsiveness to change of the POS; Patient version (tested by Wilcoxon signed rank test) N=379**

	Time 1			Time 2 (Responsiveness between time 2 and time 1)					Time 3 (Responsiveness between time 3 and time 2)				
	Mean (95% CI)	Median (Interquartile)	n	Mean (95% CI)	Median (Interquartile)	n	Z	p	Mean (95% CI)	Median (Interquartile)	n	Z	p
1. Pain	2.16 (2.03 - 2.29)	2 (1-3)	379	2.72 (2.63-2.80)	3 (2-3)	379	-8.04	<0.001	3.17 (3.05-3.29)	3 (3-4)	172	-6.85	<0.001
2. Other symptoms	2.31 (2.17 - 2.44)	2 (1-4)	379	2.83 (2.75-2.91)	3 (2-3)	379	-7.72	<0.001	3.33 (3.21-3.44)	3 (3-4)	172	-7.12	<0.001
3. Patient anxiety	2.43 (2.32 - 2.53)	2 (2-3)	379	2.85 (2.77-2.93)	3 (2-3)	379	-7.49	<0.001	3.04 (2.96-3.12)	3 (3-3)	171	-5.26	<0.001
4. Family anxiety	2.15 (2.02 - 2.27)	2 (1-3)	379	2.85 (2.77-2.94)	3 (2-3)	377	-10.01	<0.001	2.95 (2.86-3.05)	3 (3-3)	171	-3.04 [a]	0.002 [a]
5. Information	2.71 (2.59 - 2.82)	2 (2-4)	379	3.28 (3.19-3.37)	4 (3-4)	379	-8.42	<0.001	3.85 (3.77-3.93)	4 (4-4)	171	-7.60	<0.001
6. Sharing feeling	2.31 (2.19 - 2.44)	2 (1-4)	379	2.99 (2.90-3.08)	3 (2-4)	377	-9.51	<0.001	3.13 (3.05-3.21)	3 (3-3)	171	-3.40 [b]	0.001 [b]

7. Depression	2.45 (2.35 - 2.56)	2 (2-4)	379	2.91 (2.81-3.00)	3 (2-4)	379	-8.59	<0.001	3.39 (3.27-3.50)	4 (3-4)	171	-7.17	<0.001
8. Self-worth	2.57 (2.45 - 2.69)	2 (2-4)	379	3.04 (2.94-3.14)	3 (2-4)	379	-7.77	<0.001	3.42 (3.29-3.54)	4 (3-4)	171	-6.79	<0.001
9. Wasted time	1.74 (1.56 - 1.92)	2 (0-4)	379	3.54 (3.44-3.64)	4 (4-4)	378	-12.86	<0.001	3.87 (3.78-3.96)	4 (4-4)	171	-4.32 [b]	<0.001 [b]
10. Personal affairs	2.44 (2.31 - 2.58)	2 (2-4)	379	3.19 (3.07-3.30)	4 (2-4)	376	-9.35	<0.001	3.29 (3.13-3.44)	4 (2-4)	171	-3.02 [a]	0.003 [a]
Total	23.27 (22.33-24.21)	24 (14-31)	379	30.25 (29.73-30.78)	30 (26-34)	373	-13.80	<0.001	33.41 (32.74-34.08)	33 (31-37)	171	-9.71 [c]	<0.001 [c]

[a] 2 patients had missing data. [b] 1 patient had missing data. [c] 4 patients had missing data.

277 **Table 4 the percentage and level of patient-staff agreement on ratings**

	Time 1				Time 2			
	% total agreement	Weighted Kappa	p-value	n	% total agreement	Weighted Kappa	p-value	n
1. Pain	67.5	0.686	<0.001	379	72.0	0.616	<0.001	379
2. Other symptoms	57.3	0.578	<0.001	379	64.6	0.473	<0.001	379
3. Patient anxiety	52.5	0.554	<0.001	379	63.9	0.455	<0.001	379
4. Family anxiety	54.0	0.521	<0.001	378	53.6	0.305	<0.001	377
5. Information	63.6	0.583	<0.001	379	66.8	0.472	<0.001	379
6. Sharing feeling	50.4	0.522	<0.001	379	60.5	0.456	<0.001	377
7. Depression	54.1	0.476	<0.001	379	68.1	0.548	<0.001	379
8. Self-worth	55.9	0.561	<0.001	379	61.6	0.485	<0.001	378
9. Wasted time	80.5	0.728	<0.001	379	81.2	0.349	<0.001	377
10. Personal affairs	73.6	0.559	<0.001	379	73.9	0.518	<0.001	376

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References

1. World. GLOBOCAN 2012: Estimated cancer incidence, mortality and prevalence worldwide in 2012 2012 [Available from: http://globocan.iarc.fr/Pages/fact_sheets_population.aspx.
2. Lynch T, Connor S, Clark D. Mapping levels of palliative care development: a global update. Journal of pain and symptom management. 2013;45(6):1094-106.
3. Unit TEI. The 2015 Quality of Death Index Ranking palliative care across the world 2015.
4. Organisation. WH. Universal Health Coverage [Available from: http://www.who.int/mediacentre/factsheets/fs395/en/.
5. Dawson J, Doll H, Fitzpatrick R, Jenkinson C, Carr AJ. The routine use of patient reported outcome measures in healthcare settings. BMJ. 2010;340:c186.
6. World Health Assembly. WHO Strengthening of palliative care as a component of comprehensive care throughout the life course, 2014 Geneva2014 [cited 2016 16/05/2016]. Available from: http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf.
7. Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Jiang Kwete X, et al. Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage: the Lancet Commission report. Lancet. 2017.
8. Greenhalgh J. The applications of PROs in clinical practice: what are they, do they work, and why? Qual Life Res. 2009;18(1):115-23.
9. Etkind SN, Daveson BA, Kwok W, Witt J, Bausewein C, Higginson IJ, et al. Capture, transfer, and feedback of patient-centered outcomes data in palliative care populations: does it make a difference? A systematic review. J Pain Symptom Manage. 2015;49(3):611-24.
10. Bausewein C, Simon ST, Benalia H, Downing J, Mwangi-Powell FN, Daveson BA, et al. Implementing patient reported outcome measures (PROMs) in palliative care--users' cry for help. Health Qual Life Outcomes. 2011;9:27.
11. Daveson BA, Simon ST, Benalia H, Downing J, Higginson IJ, Harding R, et al. Are we heading in the same direction? European and African doctors' and nurses' views and experiences regarding outcome measurement in palliative care. Palliative Medicine. 2012;26(3):242-9.
12. Chinda M, Jaturapatporn D, Kirshen AJ, Udomsubpayakul U. Reliability and validity of a Thai version of the edmonton symptom assessment scale (ESAS-Thai). Journal of pain and symptom management. 2011;42(6):954-60.
13. Chewaskulyong B, Sapinun L, Downing GM, Intaratat P, Lesperance M, Leautrakul S, et al. Reliability and validity of the Thai translation (Thai PPS Adult Suandok) of the Palliative Performance Scale (PPSv2). Palliative medicine. 2012;26(8):1034-41.
14. Hearn J, Higginson IJ. Outcome measures in palliative care for advanced cancer patients: a review. Journal of public health medicine. 1997;19(2):193-9.
15. Collins ES, Witt J, Bausewein C, Daveson BA, Higginson IJ, Murtagh FE. A Systematic Review of the Use of the Palliative Care Outcome Scale and the Support Team Assessment Schedule in Palliative Care. J Pain Symptom Manage. 2015;50(6):842-53.e19.

16. Catania G, Costantini M, Beccaro M, Bagnasco A, Sasso L. Does quality of life assessment in palliative care look like a complex screening program? Health Qual Life Outcomes. 2013;11:7.
17. Siegert RJ, Gao W, Walkey FH, Higginson IJ. Psychological well-being and quality of care: a factor-analytic examination of the palliative care outcome scale. J Pain Symptom Manage. 2010;40(1):67-74.
18. Antunes B, Murtagh F, Bausewein C, Harding R, Higginson I, EUROImpact bo. **Screening for Depression in advanced disease: psychometric properties of two items of the Palliative care Outcome Scale (POS)**. European Association of Palliative Care; Lleida, SPain2014.
19. Bausewein C, Le Grice C, Simon S, Higginson I, Prisma. The use of two common palliative outcome measures in clinical care and research: a systematic review of POS and STAS. Palliative medicine. 2011;25(4):304-13.
20. Collins ES, Witt J, Bausewein C, Daveson BA, Higginson IJ, Murtagh FE. A Systematic Review of the Use of the Palliative Care Outcome Scale and the Support Team Assessment Schedule in Palliative Care. Journal of pain and symptom management. 2015;50(6):842-53 e19.
21. Hearn J, Higginson IJ. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. Quality in health care : QHC. 1999;8(4):219-27.
22. Streiner DL, Kottner J. Recommendations for reporting the results of studies of instrument and scale development and testing. J Adv Nurs. 2014;70(9):1970-9.
23. Mokkink LB, Terwee CB, Patrick DL, Alonso J, Stratford PW, Knol DL, et al. The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes. J Clin Epidemiol. 2010;63(7):737-45.
24. Mokkink LB, Terwee CB, Knol DL, Stratford PW, Alonso J, Patrick DL, et al. The COSMIN checklist for evaluating the methodological quality of studies on measurement properties: a clarification of its content. BMC Med Res Methodol. 2010;10:22.
25. Antunes B, Brown A, Witt J, Daveson B, Ramsenthaler C, Benalia H, et al. The Palliative care Outcome Scale family of measures; Manual for cross-cultural adaptation and psychometric validation London2012 [Available from: http://pos-pal.org/Resources.php.
26. Ho F, Lau F, Downing MG, Lesperance M. A reliability and validity study of the Palliative Performance Scale. BMC Palliat Care. 2008;7(10).
27. Sousa VD, Rojjanasrirat W. Translation, adaptation and validation of instruments or scales for use in cross-cultural health care research: a clear and user-friendly guideline. J Eval Clin Pract. 2011;17(2):268-74.
28. Terwee CB, Bot SD, de Boer MR, van der Windt DA, Knol DL, Dekker J, et al. Quality criteria were proposed for measurement properties of health status questionnaires. J Clin Epidemiol. 2007;60(1):34-42.
29. Swinkels RA, Bouter LM, Oostendorp RA, Swinkels-Meewisse IJ, Dijkstra PU, de Vet HC. Construct validity of instruments measuring impairments in body structures and function in rheumatic disorders: which constructs are selected for validation? A systematic review. Clin Exp Rheumatol. 2006;24(1):93-102.
30. Nunnally JC, Bernstein IH. Psychometric theory. 3rd ed. New York: McGraw-Hill; 1994. xxiv, 752 p. p.

31. Landis JR, Koch GG. The measurement of observer agreement for categorical data. Biometrics. 1977;33(1):159-74.
32. Polit DF, Beek CT, Owen SV. Is the CVI an acceptable indicator of content validity? Appraisal and recommendations. Res Nurs Health. 2007;30(4):459-67.
33. Guyatt GH, Feeny DH, Patrick DL. Measuring health-related quality of life. Ann Intern Med. 1993;118(8):622-9.
34. Hays R, Revicki D. Reliability and validity (including responsiveness). In: Fayers PM, Hays RD, editors. Assessing quality of life in clinical trials : methods and practice. 2nd ed. Oxford ; New York: Oxford University Press; 2004. p. 25-40.
35. Bowling A. Research methods in health : investigating health and health services. 4th ed. Berkshire: Open University Press; 2014.
36. Roach KE. Measurement of health outcomes: reliability, validity and responsiveness. Journal of Prosthetics & Orthotics. 2006;18(6):P8-P12.
37. Higginson IJ, Harding R. Outcome measurement. In: Addington-Hall JM, Bruera E, Higginson IJ, Payne S, editors. Research methods in palliative care. Oxford: Oxford University Press; 2007. p. 99-110.
38. Chaiviboontham S. Symptom Clusters in Thais with Advanced Cancer. Pacific Rim International Journal of Nursing Research. 2011;15(4):265-77
39. Molassiotis A, Wengstrom Y, Kearney N. Symptom cluster patterns during the first year after diagnosis with cancer. Journal of pain and symptom management. 2010;39(5):847-58.
40. Miaskowski C, Dodd M, Lee K. Symptom clusters: the new frontier in symptom management research. J Natl Cancer Inst Monogr. 2004(32):17-21.
41. Gysels M, Higginson IJ. Improving Supportive and Palliative Care for Adults with Cancer: Research Evidence. London: National Institute for Clinical Excellence; 2004.
42. Feinstein AR, Cicchetti DV. High agreement but low kappa: I. The problems of two paradoxes. J Clin Epidemiol. 1990;43(6):543-9.
43. Strengthening of palliative care as a component of comprehensive care throughout the life course WHA67.19 2014 [Available from: http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf.
44. Harding R, Selman L, Agupio G, Dinat N, Downing J, Gwyther L, et al. Validation of a core outcome measure for palliative care in Africa: the APCA African Palliative Outcome Scale. Health Qual Life Outcomes. 2010;8:10.
45. Harding R, Selman L, Powell RA, Namisango E, Downing J, Merriman A, et al. Research into palliative care in sub-Saharan Africa. Lancet Oncol. 2013;14(4):e183-8.